

# Newborn Screening Update

## Michigan Newborn Screening Program

October 2005

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## Introducing .....

Anyone who has requested the NBS sample card or brochure has most likely spoken with Valerie Klasko. Val is a Departmental Technician/Newborn Screening Accountant in the Bureau of Finance, Revenue Operations Division. Val has worked for the State of Michigan for 27 years. She was reassigned to the Revenue Operation Division in 2002.

Her Newborn Screening responsibilities include:

- Receive and process newborn screening orders from hospitals, midwives, doctor offices, labs and birth parents. Process invoices for accounts payable
- Review daily payments received. Follow up on payments not received.
- Balance inventory and monies to the NBS system and DCH MAIN accounting system.
- Monitor inventories of NBS cards, envelopes and brochures. Assist in the order process for NBS cards, envelopes and brochures.
- Prepare appropriate documentation for overpayment/duplicate payment refunds. Process replacement NBS cards for voided NBS cards returned to DCH.
- Like Sue Miller, she refers callers to the appropriate section based on their questions.

She has various other financial duties within the Revenue Operations Division.

Val was married on July 31, 2005 at her grandmother's 90<sup>th</sup> birthday party. She works at maintaining a positive attitude. She enjoys helping people. She has volunteered on the DCH Consumer Conference Planning Committee for 7 years. She handles the financial and food and beverage service elements of the conference.

Val can be reached at KLASKO@michigan.gov or 517-241-5583.

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## Contacts

**Program Director**  
William Young, PhD  
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**NBS Coordinator**  
Tammy Ashley, MSN CFNP  
517-335-8959

**NBS Educator**  
Midge McCaustland, RNC, MSN  
(517) 335-8588

**Laboratory Manager**  
Harry Hawkins  
(517) 335-8095

**NBS Accountant**  
Valerie Klasko  
(517) 241-5583

## How do I access the NBS Online Tutorial?

### Four Steps to Access the NBS Course

1. Enter <http://www.training.mihealth.org> into your browser. This will bring you to a listing of all the courses offered. On this page, click on "**click here to log in**" located on the last sentence of the second paragraph. This will bring you to the Learning Management System.
2. **If you have previously registered skip to #3.** If you are **not** registered into the system you must click on the "**First Time User**" Button to register. Complete the required fields (\*). Create your own User ID and password on the Self Registration Form. Click on the "Register" button and "Close Window" at the bottom. Remember your User ID and Password. Return to <http://learning.mihealth.org/SOLO>.
3. Enter your ID and Password and click on the GO button. Once at the Welcome page, you need to go to the far right corner and click on the tab "**My Learning Path**". This takes you to all of the courses available to you.
4. To find the Newborn Screening course you will need to go to page [2]. Page numbers are located at the left bottom of the table indicated by [1], [2], [3]. Once on page [2], look for "**Newborn Screening**" and click to enter the course introduction page.

Enjoy the learning experience!

Thanks to Larry Dole, MPH, and Rosalyn Beene-Harris, MDCH Genetics, for this helpful information.

# A Few Reminders ...

## **NBS FOLLOW-UP HAS MOVED!**

On Monday, October 28, 2005, the NBS Follow-up program office moved. The new address is 201 Townsend Street, Lansing. The phone number, fax number, PO box, and zip code remain the same. This move **did not** include the NBS laboratory which remains in its current location on Martin Luther King, Jr. Boulevard.

## **MARK THE BOXES RELATED TO NICU/SCN, RBC TRANSFUSION, AND TPN**

Whether or not your hospital has a NICU or SCN, it is important to mark the boxes indicating whether or not the infant was in a NICU/SCN or received TPN or a RBC transfusion (include dates of transfusion).

## **DO NOT APPLY TAPE OR STICKERS TO THE NBS CARD**

The lab has requested that you not apply tape or stickers to the NBS card. This creates a problem when the lab is separating the different sections of the NBS card. Thanks in advance for your cooperation with this request.

## **OBTAIN THE NBS SPECIMEN PRIOR TO TRANSFERRING THE INFANT**

If the infant is going to be transferred to a tertiary center, it is important to obtain the NBS specimen prior to the transfer. The provider caring for the infant at the time of birth is legally responsible to ensure that the NBS specimen is obtained.

## **NBS BROCHURE**

Check your supply stock to ensure that you have the most current copy of the NBS brochure, entitled "A First Step to Your Baby's Health." The brochure can be ordered, free of charge, by contacting Valerie Klasko at 517-241-5583.

## **NBS SPECIMEN CARD**

Check your supply stock to ensure that there is a sufficient number of NBS specimen cards to meet your needs. It is also important to check to ensure that the expiration date noted on the card is current. Repeat NBS specimen cards (pink) that are outdated do not have to be returned to the NBS Program. You may discard them in your trash. NBS specimen cards can be ordered by contacting Val Klasko at 517-241-5583.

## **NBS SPECIMEN CARD EXCHANGE**

If an error is made on the NBS specimen card prior to obtaining the blood sample tear off the top blue portion of the card and return it with the appropriate documentation to request a card exchange. If the blood sample has been initiated on the NBS card it is important to remove the filter paper prior to returning the card for an exchange. NBS cards that are received with blood on the filter paper will be processed by the lab.

## **PARENT REFUSAL OF NBS**

If a parent refuses the NBS for their infant, it is important that the hospital or practitioner complete documentation to ensure that the parent was fully informed of the potential consequences of their refusal. Include a copy of this documentation and/or the "Dissent Form" signed by the parent when returning the NBS card for exchange. It is important to send documentation of the parent's refusal for the Newborn Screen to the NBS Program even if you are not requesting a NBS card exchange.

## **NEWBORN SCREENING EDUCATION**

Midge McCaustland, RNC, MSN, is available to provide a variety of educational materials and presentations. She is available for one-on-one consultation and group presentations. If you would like her to speak to your staff or at your conference, call her at 517-335-8588 or send her an e-mail to [mccaustlandm@michigan.gov](mailto:mccaustlandm@michigan.gov).

## **NBS COORDINATOR**

Tammy Ashley, MSN, CFNP, recently began her role as the NBS Coordinator. She will be working closely with the Medical Management Centers and the families of children diagnosed with the various NBS disorders. She can be reached at 517-335-8959 or [ashleyt1@michigan.gov](mailto:ashleyt1@michigan.gov).

## A Mother's Story

Our two boys, age 2 and 5 were thrilled with the arrival of their new baby sister, as were my husband Tom and I. In my professional opinion as a physical therapist and as Kelly's mom, she was a perfect baby. As Kelly approached the ages of three and four, it became obvious that she was becoming more and more agitated and was losing fine motor skills. Just before starting kindergarten, she was diagnosed with subluxed lenses in both eyes and high myopia. We prayed that the correction to her vision would improve her frustrations and the delays we were seeing. After a thorough work up by a pediatric neurologist, Kelly was diagnosed with Homocystinuria.

I have worked with many disabled children but I had never heard of Homocystinuria. It was frustrating to even find information on the disorder. What I did find was scary. The information was old and based on some worst case scenarios, as most children were diagnosed at death or because of a catastrophic thromboembolic event.

The treatment for the disorder seemed almost worst than the disease itself. Kelly was 6 years old and lived to eat. All her favorite foods were taken away and she was forced to take a nasty tasting medical formula. It would be difficult to accomplish this with a normal child but Kelly was hyperactive, easily frustrated and prone to violent mood swings. In addition, I had to cut back my work hours to take care of her, her diet and her many doctor's appointments at the same time the additional financial burden of paying for the expensive foods and medical formula were added to our budget.

Well meaning friends and relatives gave advice about vegetarian diets, aloë treatments, prism glasses and faith healers but the day to day frustration of getting Kelly to take her formula and succeed on the new diet was a one-mom show. Kelly went on a food strike. She acted enthused about the low protein foods I cooked, pushed them around the plate, but never really actually ate anything. All the expensive and difficult to prepare foods went from the stove to the plate to the trash. Kelly did not care for the high fat, high sugar foods we tried to lure her with to maintain or improve her weight. It was scary.

Last year, Kelly had a severe sinus infection. The MRI showed the affected sinus pushing on a cranial nerve, requiring immediate surgery. It also showed that her internal carotid arteries were in the process of narrowing.

Kelly is 16 and a sophomore in high school. She attends basic and regular classes and gets support services in the form of accommodations for her visual impairment and help with her resource teacher. She will be unable to drive safely. Kelly loves movies and animals. She has two new pocket beagle puppies in addition to her 10 year old beagle mix, Charlie. Kelly has generously agreed over the years to be interviewed by the first year medical students at MSU, be the "case of the week" at pediatric grand rounds and demonstrated and explained her disorder and its manifestations to countless new doctors in training (as we live outside of Lansing and her physicians frequently have students shadowing even in their offices). She is happy that babies with Homocystinuria can now be diagnosed at birth or shortly after as a result of newborn screening.

She knows that she is at a disadvantage because of her late diagnosis. Her ability to comply with her diet and take the formula are forever affected by the late start she got. She is brave about the damage that happened to her vascular system, nervous system, teeth, eyes and joints. Kelly has a spirit that is unstoppable. She is an inspiration to those around her with her quick wit and love of life. She never fails to entertain or cut to the chase. She is grateful for those who have truly supported her and she can see right through those who are just patronizing her but without any ill will. She is a champion for people who are different. Just as I thought when she was born - the perfect daughter!

Submitted by Therese — Mother of Kelly, non-B6, nonB12 responsive Homocystinuria

## Information Sharing ...

Hospitals and other providers are invited to share information on their practices, policies, procedures, and experiences in an effort to improve the NBS process. This information is not to be considered a "requirement" of the NBS program. It is merely a "sharing of ideas" that you may choose to evaluate for use in your facility. If you would like to contribute an idea to share, please e-mail the information with a contact name, phone number, and permission to include the information in the NBS Update to [mccaustlandm@michigan.gov](mailto:mccaustlandm@michigan.gov).

## Ideas to share

### **National Folic Acid Awareness Week – *Folic Acid: You Don't Know What You're Missing!***

The National Council on Folic Acid is launching National Folic Acid Awareness Week, January 9 – 15, 2006 – *Folic Acid: You Don't Know What You're Missing!* The Michigan Department of Community Health Birth Defects Program is promoting National Birth Defects Prevention month and is joining with the National Folic Acid Council for folic acid week. The week will focus on making people aware of folic acid consumption as a key strategy for optimal health.

In recent years, numerous scientific studies have pointed to the importance of folic acid in helping to prevent neural tube birth defects and helping protect men and women from a range of chronic diseases. However, despite the science – and recommendations by numerous top health authorities – over half of all American adults are not getting enough folic acid on a daily basis.

Folic acid is a B-vitamin necessary for proper cell growth. The U.S. Public Health Service recommends that all women of childbearing age consume 400 micrograms of folic acid by taking a daily multivitamin and eating fortified grains, in addition to a variety of foods as part of a healthy diet. In particular, women of childbearing age should take folic acid to help prevent a pregnancy affected by a neural tube birth defect (NTD), a serious birth defect of the brain and spine. Spina bifida, the most common NTD, is the leading cause of childhood paralysis and presents lifelong challenges for affected families.

Beginning in 1998, the Food and Drug Administration required the addition of folic acid to enriched breads, cereals, flours, pastas, rice, and other grain products. According to the CDC, since the introduction of fortification, rates of NTDs have decreased by 26 percent.

Each year, 80 Michigan babies are born with an NTD. Taking 400 micrograms of folic acid before and very early in pregnancy, from a multivitamin or fortified foods, can help prevent NTDs by up to 70 percent. Considering that half of all pregnancies are unplanned, it is especially important that all women of childbearing age take folic acid daily to help prevent NTDs – even before they are thinking of becoming pregnant.

Emerging research shows that folic acid has health benefits beyond preventing neural tube birth defects. Folic acid may reduce the risk of other birth defects, such as cleft lip, cleft palate, and heart defects. It may also reduce the risk of cardiovascular disease; colon, cervical, and breast cancer; and Alzheimer's disease. Folic acid in combination with vitamins B12 and B6 appears to protect the neurons critical for learning and memory that are destroyed as plaques accumulate during Alzheimer's disease. We encourage everyone to take 400 micrograms of folic acid every day. The preliminary research findings are exciting, and we believe that taking adequate amounts of folic acid can be beneficial for men and women of all ages.

For more information about folic acid and National Folic Acid Awareness Week, visit the website of the National Council on Folic Acid, [www.folicacidinfo.org](http://www.folicacidinfo.org) and the Michigan Department of Community Health, [www.MIgeneticsconnection.org](http://www.MIgeneticsconnection.org).

A special thanks for the above information that was submitted by:

Nelda Mercer, MS, RD, FADA

Nutrition Communications Consultant

Contractor, Michigan Department of Community Health, WIC Division

Folic Acid Coordinator/Educator, Genetics and Newborn Screening

# **Michigan Department of Community Health**

Genetics and Newborn Screening/Public  
Health Genomics

## **Has MOVED!.....**

**New street address:**

**201 Townsend St. 4<sup>th</sup> Floor**

**Lansing, MI 48913**

**Mailing address:**

**P.O. Box 30195**

**Lansing, MI 48909**

Our e-mail addresses and phone numbers have  
remained the same

Our staff include: Karen Andruszewski, Ann Annis Emeott,  
Tammy Ashley, Janice V. Bach, Rosalyn Beene-Harris, Champa  
Bhatia, Mark Caulder, Debra Duquette, Joan Ehrhardt, Valerie  
Ewald, Andrea Howard, Carrie Langbo, Rebecca Malouin, Midge  
McCaustland, Sue Miller, Jane Simmermon, Mary Teachout,  
William Young

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A blue oval containing the text "Michigan Newborn Screening Program" in white.

Michigan Newborn Screening  
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